

CHAPTER XI

SERVICE DELIVERY IN RURAL AREAS

by Dennis Popp

The special needs of rural areas seem to have been neglected in the nation's efforts to recognize and cope with the problems of mentally retarded persons. When the federal government arranged in 1964 for "comprehensive" state-wide mental retardation studies throughout the country, only a very few states even mentioned the specific needs existing in rural areas. Yet rural areas still comprise a large part of the nation, from the farm lands in the central United States to the Indian Reservations in the Southwest; from the mountain sections of some eastern states to those of the Northwest.

A report of a community service demonstration project carried on in six sparsely populated counties in Wisconsin cogently summarized the special problems faced by mentally retarded persons in rural areas:

- A. In a rural area the understanding and awareness of the retarded's needs and the subsequent impetus to serve him has suffered from the relative lack of exposure to publicity, information, and educational effort.
- B. Services for the retarded have not developed in rural areas due to the mechanical problems involved in bringing people together in an area of low population density.
- C. In a rural area there is often a lack of facilities such as day care, sheltered workshop, and special classes to serve the retarded.
- D. Most rural areas lack diagnostic and treatment centers.
- E. Rural areas lack an organizational structure for proper identification, treatment, and referral of the retarded and their families.
- F. There is an extreme lack of trained professionals, such as psychologists, social workers, public health nurses and physicians, who can offer service to the retarded or their families.
- G. The rural retarded and their families have long been

unaware of any alternatives to strict custodial care in the home.

H. People in rural areas often have low expectations for their normal child, as well as the retarded, and are unable to see the value of training and education. I. There is often a stigma attached to family counseling in a rural area, and the fixed point of referral may be located in a clinic or welfare department. Where little stigma is attached, such as the public health nursing service, this office is understaffed in a rural area. J. Neighbors in a rural area often have less experience with and understanding of the retarded child than their urban counterparts.

K. Parents of the retarded in a rural area are often poor and cannot afford the cost involved in transportation or the child care necessary to attend parent group meetings or take advantage of counseling and diagnostic services for their retarded child.¹

Increasing resources available, innovations in service delivery methods, and building upon the unique strengths of rural areas may alleviate some of these factors. But many will require new organizational patterns. Many services formerly state-administered or provided centrally will have to be administered on a decentralized basis, often in cooperation with counties. At the same time, other services delivered locally to "normal" persons will have to be supported with special resources from a regional level. A region may be a combination of two adjoining counties, a large segment of the state, or even a territory encompassing areas of several adjoining states. The involvement of a multiplicity of governmental units with different levels of authority and different functions clearly necessitates energetic communication, coordination, and cooperation. But it can be done. Interstate projects for rural mental retardation services, for instance, were developed in Indiana, Kentucky, and Ohio, and between Arizona, Colorado, New Mexico, and Utah.

In actual service delivery the great distances in rural areas require different solutions depending on the nature of service. Individualized services such as guidance and assistance to a mother in managing her severely handicapped infant would suggest that the service be brought to the home. On the other hand, schooling and vocational services require either availability of daily transport or, in cases of unusual distances, a

¹ *A Community Service Demonstration Project for the Mentally Retarded in a Rural Area*. Grant No. MR 5301—A65, April 4, 1966 (mimeo). Central Wisconsin Colony, Madison.

boarding arrangement away from home, preferably for four nights only.

But, despite their small population groupings, diverse political influences, and lack of public and professional leadership, rural areas do possess great strengths, unknown to urban and suburban areas. Rural areas have a cohesive social and cultural pattern that demonstrates concern and acceptance for all "members." A strong local pride is easy to self-generate on behalf of "meeting the needs of our own." Small populations also facilitate a personal knowledge of one another's abilities as well as limitations, leading to formation of more personal relationships.

Typically, however, only one or two persons' energy and guidance lead to the development of services. As long as this energy is present, the service remains. When the energy fades, so does the service. If we are to overcome the current lack of comprehensive rural services and the resulting human suffering, we will need greatly increased efforts to build on local strengths and continued innovation in delivery methods. The following pages describe some positive efforts which build upon local strengths and which use innovative methods.

CASE-FINDING, INFORMATION AND REFERRAL SERVICES

For services to be given, the service provider must identify those needing a service (case-finding); and, on the other hand, the parent-consumer must be able to find out where to turn for assistance (information and referral).

In the absence of the health and welfare agencies typically found in cities, rural areas offer informal informational networks which can help find people needing services. Because through their general knowledge they can assist people to enter the service system, people in these networks are sometimes referred to as "gate keepers." A study² made in Vermont (designated by the U.S. Census as the most rural State in the Union) identified mentally retarded individuals in a two-county region and found that such persons as town clerks and postmasters had more such information than physicians and public health nurses. Because of case-finding's being so informal and unconnected

² Bruce W. Lagay, *"Mental Retardation in a Rural New England Area: The Use of Gatekeepers to Identify Retarded Persons in the Community."* Doctoral dissertation, Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, Waltham, Mass. 1972.

to service providers, information and referral has also been informal and undesigned. Many parents have, therefore, been uncertain where to turn, whom to talk to, and how to learn what the future may be like for their child.

A solution to this problem, first suggested by the President's Panel on Mental Retardation in 1962, is the establishment in a given area of a "fixed point of referral." The Wisconsin rural community service project mentioned earlier approached such a solution by establishing in each of its six counties a fixed point of referral in the person of a specifically assigned staff member of a local agency. In two cases this was the county welfare department, in another two the mental health clinic, in one the public health nursing service, and in the remaining one the sheltered workshop.

These workers spent more than half their time on individual contacts, general evaluations of the presented problem, referrals to the appropriate agency or agencies, and counseling with families so that their initial fears could be alleviated and parents could develop the strength to seek further help. The workers spent the rest of their time on community education, consultation to agencies, and stimulation of new or expanded services. This system succeeded so well in the six-county demonstration area that Wisconsin is now establishing "fixed points of referral" in all the counties.

PREVENTION

In the past, because of the distances, lack of knowledge, lack of manpower, and lack of available media, thinking about prevention within rural areas was difficult. It once seemed administratively impossible to inform every expectant mother of her need for immunization against measles or even to have each one receive prenatal examinations. But today prevention in rural areas is being attacked on a regional and even statewide basis. The University of Nebraska Medical Center,³ for example, has developed a mass public education program which stresses early and frequent prenatal examinations of mothers whose unborn babies may be at high risk. The Medical Center first aims to reach out with preventive information and to help all mothers of potentially high-risk infants during their prenatal stage. As a secondary prevention strategy, when a newborn child does

³ University of Nebraska Medical Center Report to the President's Committee on Mental Retardation at a meeting in Kansas City on September 21, 1973, Gerard Van Leeuwen.

show definite symptoms of problems associated with mental retardation, the Medical Center has a specially equipped van and a plane to bring in the mother and the infant. This dual strategy of primary prevention and very early intervention has significantly reduced lasting handicapping conditions.

Continued mandatory screening and inoculation of children at their entry into public schools will help to reduce the number of handicapped persons in rural areas. New provisions for early screening and medical services under Title XIX of the Social Security Act could greatly help a largely unserved population. This program of medical screening, diagnosis, and treatment of health problems in economically deprived families should prevent many of the problems we now find causing long-term handicapping conditions.

DIAGNOSIS AND EVALUATION

In most rural areas few professional people are available to assess developmental problems and to plan for appropriate treatment and training. Referral for a comprehensive diagnosis, including biological, medical, psychological, psychiatric, educational, social, and other necessary developmental tests may be available at only one or two very distant locations, usually a state university medical center or a state mental retardation training facility. For diagnostic information to be useful to those who seek it—parents and other community agency personnel—the distant diagnostic facility must share it in clear, understandable language. Diagnostic findings must lead to treatment and training that can be carried out by minimally trained or non-specialized staff. If appropriate goals, objectives, and methods are clearly determined, most treatment and training can be conducted locally. If these measures are taken, only rarely, when specialized and intensive treatment by a highly trained professional is required, will the handicapped individual have to be treated in a distant location.

Sometimes one cannot travel away from home for diagnosis and evaluation. In this case, even the highly specialized services should come to the family. Public and private agencies can purchase specially designed and equipped mobile vans for medical, educational, and social evaluations on a district or regional level. (These mobile facilities can be adapted periodically to meet the needs of various other programs as well.) In particular,

mobile vans can be used to train parents and to equip and support professional personnel who come to work in rural areas.

HOME TRAINING SERVICES

In all areas of the country parents with severely retarded infants and young children commonly find themselves facing the task of meeting their child's special needs without helpful continuing guidance. This experience is particularly damaging in rural areas because there is so much less chance of helpful contacts with other parents of handicapped children or with knowledgeable professional workers. Feeding problems, sleeping problems, listlessness, hyperactivity, and lags in motor and speech development greatly concern parents; they need guidance and practical help.

This help may come to the parents through home training specialists employed by a health, mental health, education or welfare agency, through a public health nurse or, especially in rural areas, through a home demonstration agent from the Cooperative Extension Service of the U.S. Department of Agriculture. Ideally, the home training specialists should act as extended arms of local agencies with which they can consult about special problems they encounter during home visits. A good though rare example of this type of service was developed in 1969 in Portage, Wisconsin, originally with federal funds, but now maintained by contributions from 23 school districts.

The Portage Project serves a group of rural counties with numerous small communities in central Wisconsin. On its staff, the Project has ten to twelve specially trained teachers who visit the homes of preschool children with mental and physical impairment, many of them multiply handicapped.

As children were being identified it was clear that classroom programs could not be provided due to the cost and responsibility of transporting very young handicapped children great distances. In addition, even when several children were identified within a smaller geographical area, i.e., one school district, the variance in chronological ages, functioning levels and handicapping conditions precluded establishing classroom programs. In addition,

⁴ See Jennifer Howse, *Preschool Instruction Mobile Facilities: Description and Analysis*, Southeastern Education Laboratory, 1971. If the mobile unit is used frequently, it should be self-propelled rather than the trailer type. Ordinary small camper vans have been modified for use; truck vans have been used to transport bulky and expensive diagnostic equipment.

classroom programs would severely limit parent involvement due to the geographical and psychological distances between home and school. Thus, a major program decision was made: all instruction would take place in the parent's and child's natural environment—the home.

Thus, the Portage Project is a home teaching program attempting to directly involve parents in the education of their children by teaching parents what to teach, how to teach, what to reinforce, and how to observe and record behavior.⁵

With the aid of a developmental check list the teacher, who visits the home generally once a week for about two hours, helps the parents to see how their child is functioning, determines what they want to teach their child during the next week, records whether the child has progressed, and then has this reviewed by a supervising teacher. The traveling teacher not only gives parents the encouragement they need, but also provides suggestions for new techniques and methods. This project has demonstrated that parents can objectively evaluate their children, teach them, and joyously watch them grow and develop. Where more complicated problems suggest help from other agencies, the teacher can make referrals or at least assist parents with them. When major diagnostic work-ups are required, the teacher, if at all possible, will accompany the parents and the child to the clinic. She is then able to share her observations with the clinic and, in turn to receive a first-hand interpretation of the clinic's observations.

OTHER MEANS OF HOME TRAINING

In some regions, inaccessible or very difficult transportation routes and insufficient personnel prohibit frequent contacts. Still, evaluation and training can be brought into the home. Correspondence courses can be developed (as has been done for many years in New Zealand).⁶ The parents receive weekly prescriptive material for use with their handicapped child. Since most homes today have either a radio, a television, or both, retardation services should design specific training programs for radio and television broadcasting at predetermined intervals.

⁵ David E. Shearer and Marsha S. Shearer, *The Portage Project: A Model for Early Childhood Intervention*. Prepared for the conference on Early Intervention for High Risk Infants and Young Children, May 5-8, 1974, Chapel Hill, North Carolina. (Mimeographed.)

⁶ R. Winterbourn, "Home Training Through Correspondence—a New Zealand Programme." In: *International Child Welfare Review*, 19A, 1965.

Television can also be used to train and support parents who are not as isolated. Some public libraries serving rural areas work hard to have available helpful literature for parents of handicapped children and also to present information on how to obtain appropriate films. Telephone, television, radio, and periodicals can also tremendously help the isolated professional and paraprofessional located in rural areas, helping them to keep abreast of current knowledge, philosophies, principles, and techniques.

INFANT DEVELOPMENT CENTERS

Parents can profit greatly from contact with other parents and with professionals associated with the facilities serving their child. Parents in rural areas (where highways are accessible) will drive sixty to ninety miles one way to attend infant developmental programs. They need both the opportunity to relate to other parents of handicapped children and to observe how easily others handle their children. Infant development centers could demonstrate how specialists from different areas can work together to help each child and his parents through explicit steps of development. At these centers the parents also could learn what toys help best with growth and development and how they can build their own toys with simple materials. They should be able to check out toys from the centers just as they would borrow a book from the public library. As the communications media present additional information on growth and development and as more local programs are established, parents can become more secure in raising their handicapped children at home. They no longer have to feel rural isolation.

EDUCATIONAL SERVICES

With the federal courts reemphasizing the right of every child to have an education, new administrative systems and methods are needed to provide educational services in rural areas. Above all, the integration of a severely handicapped child into regular public school buildings is requiring schools to plan for space and equipment which they consider unusual because it is special. These requirements are actually no more unusual than that space and equipment required by other students

enrolled in special areas of learning such as chemistry, wood-working, home economics, and so on. A special effort must provide multiply-handicapped children with classroom space without architectural barriers.

Special educational services in rural areas will also call for an expansion of the traditional school bus systems to include specially designed buses to transport multiply-handicapped children in wheelchairs. Since they travel up to sixty miles one way to school, these buses may also carry teachers and training equipment to provide educational and social stimulation to the students.

As school districts become unified in the delivery of special services, there will also be an increase in the recruitment and use of temporary residential programs for five days and four nights. These temporary living arrangements are repeating a historical practice of educational attendance in rural areas; many years ago all of the children in some rural areas were "boarded out" when there were insufficient numbers of schools available for those who wanted to go beyond the eighth grade. A variety of boarding facilities are necessary in rural areas since most "temporary parents" have preferences for the degree of handicapping conditions they can accept in a child. A system must not only find understanding and accepting boarding families but also give them needed back-up services to cope effectively with any special problems the children might present.

ADULT SERVICES

As another major problem, rural areas lack varied work opportunities for individuals or contract work for those adult developmental facilities which use work as the primary training method. For many years simple farming or service job opportunities were the only choices.

More recently, because the agricultural industry became mechanized, opportunities were limited to truck gardening and tasks identified with migrant farming. But the rural environment is now beginning to offer new opportunities to retarded workers.⁷ In a southwestern state, for instance, rehabilitation authorities initiated a system which organizes and employs retarded young men in work crews of six and assigns them to tasks in state parks. A similar project has worked well in the

⁷ See *Employment Methods, for Severely Physically Disabled*. SRS-DD Grant to United Cerebral Palsy of Kansas, #57-B-603, 1973.

park system of a midwestern state. Irrigation, hoeing, and the spraying of citrus and avocado groves have recently been found to offer productive jobs for retarded workers. Groups of retarded workers have been successfully placed with the poultry industry, both on farms and in processing plants. In several of these agricultural occupations both young men and women are employed.

As industries relocate in rural areas and a variety of jobs and subcontracts become available, additional work opportunities for rural mentally retarded young people should materialize. It has been demonstrated that industries can profitably employ handicapped workers, and some are now hiring more multiply-handicapped adults. As industries set aside specially designed space and develop specialized tools and equipment, handicapped persons will integrate into production lines and labor unions. Here again only specialized housing and other ancillary support services can allow this integration to continue successfully.

As industrial development has expanded in rural areas, rural schools in midwest and western states have played a significant role in widening the range of job opportunities for retarded people by introducing work-study programs. When such programs have extended over three years for the individuals involved, substantial vocational benefits have been achieved. Once such a program has gained acceptance and approval, placement opportunities multiply. A cooperative tricounty special education work-study program lists no less than twenty-four different types of work facilities in which students have been trained and employed.

Increasingly, more severely handicapped adults in rural areas can work in work activity centers, sheltered workshops, and adult day-care centers. Because of the difficulties in subcontract procurement some of these centers have been able to provide only "busy" activities. As isolated centers, they are now realizing that they do not have sufficient trained personnel or subcontracts to deliver appropriate treatment and to design specialized training services. Consequently, these centers are entering into contracts with a variety of service agencies at a regional or multicounty level, and these contracts become more and more prevalent as planning becomes more sophisticated at the regional level.⁸

⁸ This trend is well depicted in the philosophy and principles of the new *Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities*. Accreditation Council for Facilities for the Mentally Retarded. Chicago, 1973.

RECREATIONAL SERVICES

While opportunities for adequate schooling for even the more severely retarded child are improving year by year, recreation remains a critical problem, particularly in rural areas. Fortunately, in a number of states the 4-H youth clubs, organized under the Cooperative Extension Service of the U.S. Department of Agriculture, have recognized this problem and come up with a twofold answer. Special 4-H Clubs have been organized to meet the needs of children in specialized classes, and "regular" 4-H Clubs have taken an interest in offering recreational opportunities to retarded children. While some 4-H Youth Members have volunteered as camp staffers, others are helping retarded young people with grooming and other social training. Some of the Extension home demonstration agents also have developed recreation activities such as creative art projects and nature study.

In some areas "Scouting for the Handicapped" programs might be available. Youth groups affiliated with the National Association for Retarded Citizens also have developed recreational programs for young retarded adults, and some of these have been extended to rural areas.

COUNSELING

Counseling services must be available throughout the lifetime of a handicapped person. It is a difficult decision for parents to choose to place their young child in even a temporary boarding home in order to attend school. The emotion experienced by most parents when their child first enters school is doubly experienced by these parents. They feel that only they know the sudden occurrences which can place their child in a dangerous situation and which require immediate, knowledgeable help. However, with expert counseling and understanding, school and community professionals can make this transition less painful for both parents and child. Of equal importance is the availability of counseling to the retarded person in adolescence and adulthood as he leaves the protection of home and school and faces the challenge of life in the community. Only a very few rural areas have a counseling agency, let alone a specialized service geared to handicapped individuals. For the time being, reliance must be placed on volunteers and informed networks.

ETHNIC SERVICES

In some rural areas the majority of the population may represent a single ethnic group. An outstanding example of an ethnic group which initiated services for their handicapped members is the Navajo tribe. Other Indian tribes, including the Mountain Utes, were also involved, and it was an interstate effort as well. The states were Arizona, Colorado, New Mexico, and Utah.

The planning effort included representatives of the following agencies from each state: The Bureau of Indian Affairs, the State Coordinators of Mental Retardation Programs, the Governor's Planning Office, the State Special Education Division, the State Vocational Rehabilitation Services, and the State Public Health Department. Through interagency planning with these tribes and tribe leadership, members of the Navajo tribe were trained to establish and staff a fixed point of referral to provide counseling services, child and adult training services, and special education services. Ethnic groups in most rural areas would need to involve many of the same agency representatives in planning efforts for comprehensive services because overlapping political jurisdictions and several state and federal agencies will provide these services.

CONCLUSION

In the beginning of this chapter we spoke of some of the problems associated with planning and providing services for handicapped citizens in rural areas. We have attempted to point out how various areas throughout the United States are overcoming these problems. Because of the vast geography and the resulting need for specialized transportation and housing, providing comprehensive services in rural areas will always cost more than in urban and suburban areas. But when measured against the human and economic price of unattended problems, these costs should not deter us.

We have made significant strides in the last twenty years as we have proven that parents isolated in rural areas can provide excellent care and training for their handicapped child when given the proper support and guidance. Given the creativity and support of home care services and understandable, clear-cut professional guidance, the rural parents of a handicapped child need not send him away in their quest for services, nor need the child and family languish in need and neglect.

Parents and professionals must continue to demonstrate a creative approach to the problems presented within large rural areas. They must plan for and develop methods and techniques that guarantee that handicapped people receive proper training and treatment at the appropriate time. The pride of people living in rural areas still runs deep, and this pride will enable them to demonstrate a self-determination to meet the needs of their fellow citizens.

But rural areas must not be left alone with their pride as their major strength. To deliver needed community services, rural areas themselves need to receive much greater administrative and financial attention from state and federal governments. In a technological country, rural areas should be able to expect far greater innovation in service delivery methods through greater research and development funds.